Guidelines for Sharing Research Data on Human Participants

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CROSSDA - Croatian Social Science Data Archive

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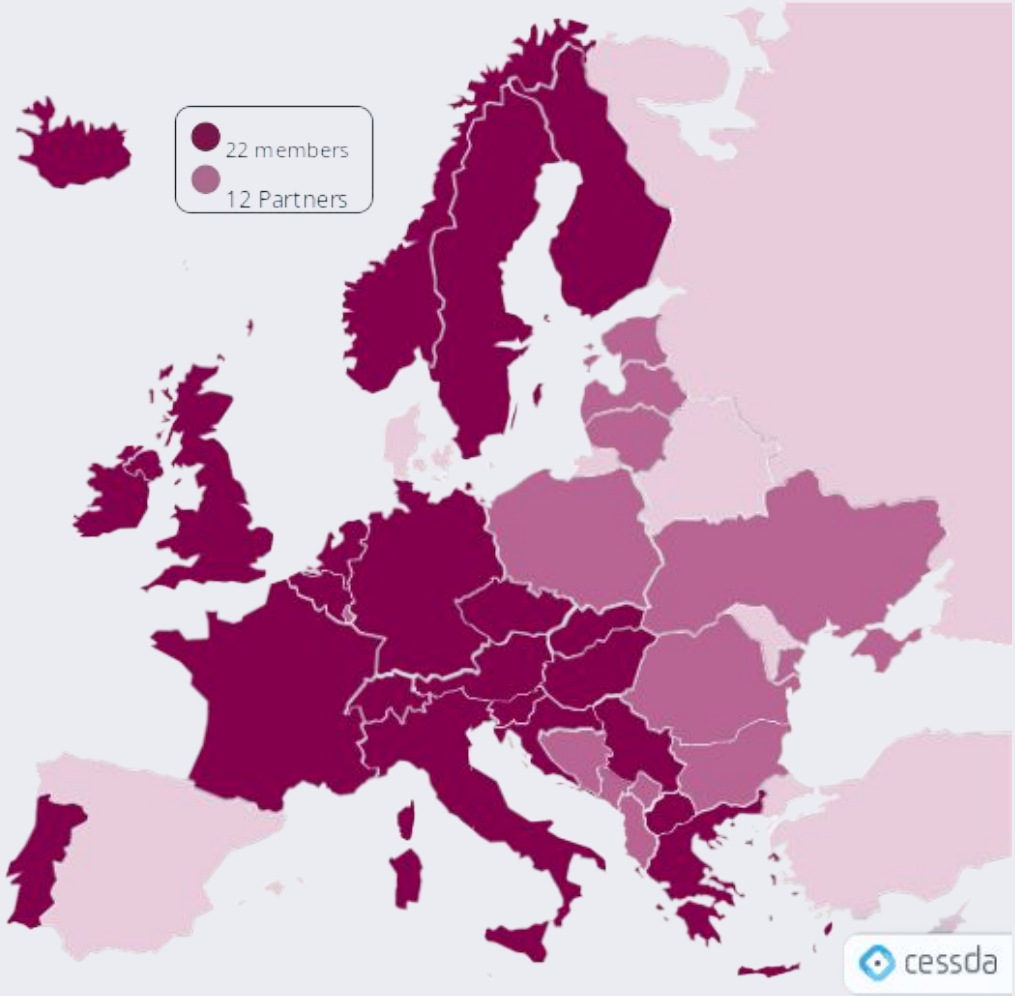
Why the Guidelines?

CESSDA

Is the Consortium of European Social Science Data Archives (Service Providers)
A true European research infrastructure.

Mission

To provide a sustainable research infrastructure that enables the research community to conduct high-quality research in the social sciences
to contribute to effective solutions to the major challenges facing society today.



Data Sharing Barriers

- Privacy, confidentiality, and ethics
  - Participant consent concerns
  - Concerns on disclosing personal information
  - Sensitive data issues
- Intellectual property rights issues
- Resources constraints
- Priority in publishing results and fear of scooping
- Fear of misinterpretation and misuse
- Perceived lack of interest
- Data quality concerns
- Cultural and institutional resistance
- Limited incentives and recognition

Photo by Kyle Glenn on Unsplash

Privacy, confidentiality, and ethics

Confidentiality and consent	• *If I ask my respondents for consent to share their data then they will not agree to participate in the study.* • *I have made promises to destroy my data once the project finishes.* • *My data have been gathered under complete assurances of confidentiality.*
Concerns on disclosing personal information	• *I am doing quantitative research and the combination of my variables discloses my participant's identity.* • *It is impossible to anonymise my transcripts as too much useful information is lost.* • *I have collected audiovisual data and I cannot anonymise them, therefore I cannot share these data.*
Sensitive data issues	• *I am doing highly sensitive research, therefore I cannot possibly make my data available for others to see.*

Will they really not agree to participate?

- What if participants are aware that their answers will be used for a greater good, such as in new research, to improve public policies related to problems that are being researched, or as a proof that research results were calculated correctly?
- Personal data should be stored securely for a specified period of time, and deleted when not needed any more.

If participants trust you, can they also trust someone you trust?

- Rather than believing that confidentiality can only be achieved by promising that the data will be seen exclusively by you and your team, consider extending that promise to include that the data will be used by you and those you trust.
- Explain that data will be shared with other researchers responsibly, and that data sharing is desirable practice in contemporary research conduct.

Have in mind that enabling access to data is not only about open access to data!
(stil can be FAIR)

Enabling access to data is not only about open access to data

- Not all data should be shared openly with everyone.
- Data should be anonymized and shared under specific terms and conditions to ensure its appropriate use.
- Access to data can be restricted for specific purposes, such as research, and granted only to researchers affiliated with academic institutions - relying on trust mechanisms, contracts.
- Data users may be required to undergo training to ensure they understand how to handle the data responsibly responsibly.

Priority in publishing results and fear of scooping

- Allow a period during which only you and your team can utilise the data for publishing papers - not too long!
- You are the one who knows your data best.
- Attempts at theft in science are actually quite rare. Also, self-correcting mechanisms.
- Treat the published dataset as a separate product of scientific work, an entity that can be cited. Informe everyone in advance that this was your idea.
- Consider the various purposes of data sharing.

Fear of misinterpretation and misuse

- Provide comprehensive documentation and metadata alongside your data to facilitate understanding and interpretation by other researchers.
- Make sure your data is accurate, reliable, and trustworthy by checking it thoroughly.
- Establish formal data sharing agreements with researchers or institutions interested in accessing your data.
- Keep an eye on how others use your data by tracking its usage (data citations practices).

Part 2. Archiving and sharing data

- Data management is important!
- Steps in data sharing
  - Define data sharing objectives
  - Select what to share
  - Select an appropriate service/repository
  - Prepare data and documentation for archiving and publishing
  - Determine access rights and licensing
  - Sign the deposit agreement
  - Submit data and documentation to a selected repository
  - Be available for revisions after your dataset has been reviewed by repository staff

Guidelines are available on Zenodo

https://10.5281/zenodo.15267610

We welcome your feedback and help in polishing the Guidelines.

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